The experience of stigma among adults with Tourette's syndrome.

Executive Summary

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"Never laugh at other people's disabilities. Unless they have Tourette's, because how can you not?"

Executive Summary

Stigma devalues individuals depriving them of full social acceptance (Goffman, 1963). Yet despite growing awareness of the negative consequences of stigma for people with disabilities (see Corrigan, Patrick & Bink, 2005; Liamputtong, 2013; Tang & Bie, 2016) our study is one of the first to systematically examine the experience of stigma from the perspective of adults with Tourette's syndrome.

A neurological condition characterised by tics (involuntary unwanted movements and/or vocalisations that can vary in frequency, complexity and intensity (American Psychiatric Association, 2013), TS is often accompanied by obsessive–compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD), anxiety disorders, and depression. Despite popular stereotyping of the condition as the 'swearing disease' (see Calder-Sprackman, Sutherland, & Doja, 2014) by virtue of coprolalia (involuntary utterances of obscene words), this symptom of TS is fairly uncommon (Freeman et al., 2009). Whilst some progress has been made to de-emphasise this aspect of the condition (see documentaries such as 'Tourette De France' and 'Twitch') TS is still generally portrayed in the media as synonymous with uncontrollable cursing and unpredictable behaviour (Malli, Forrester-Jones, & Murphy, 2016).

The aims of our UK study were:

1. to assess the extent and nature of stigma as experienced by people with TS;
2. to understand how stigma impacted the quality of life of adults with TS;
3. to gain coping strategies adopted by individuals with TS to cope with stigma.

Our overall objective was to inform current policy and practice around TS.

We used a mixed-methods study design. Tourettes Action support groups and an advisory group including individuals with TS and their family carers helped design the study. Participants were recruited via a video https://www.youtube.com/watch?v=XVQTO0wew8A posted on relevant platforms (e.g. Tourettes Action, Facebook, Twitter) and through the Research Participation Registry of Tourettes Action database as well as snowball sampling. The study took place between from 2019 to 2020 and was given a favourable opinion by a University of Kent Ethics Committee (REF: 11/2018).

In addition to digitally recorded face-to-face on-line interviews, an on-line survey included the following measures:

- *Discrimination and Stigma Scale (DISC-12)* - assessing the degree to which people with TS experienced stigma and discrimination in their everyday lives, and
- *Perceived Quality of Life* (Patrick et al., 1998; 2000) - to assess individuals' subjective evaluation of their quality of life.

Quantitative data was subjected to statistical analysis and qualitative data was analysed using thematic analysis.

Sample characteristics

199 adults with TS completed the survey. The mean age of participants was 31 (age range 18-73). 48% were female, 46% were male, and 6% identified as "other gender". Over half the sample identified as White British (67%) and the majority (n=125) were single. The majority (56.2%) reported a tic onset between the ages of four to eight, whilst a small number reported an adult onset. Additional (one or more) mental health conditions or developmental disorders were reported by 76.6% of the participants, including Anxiety Disorder, OCD, ADHD and Autism.

20 adults (14 men and 6 women with a mean age of 33 (range: 20-71) self-identifying as having Tourette's were interviewed. 15 reported comorbid diagnoses, including OCD, anxiety, autism, ADHD, dependency, eating disorders.

Quantitative Findings

- Participants reported experiencing discrimination in numerous life domains and most prominently in education (75.7%), interpersonal relationships (71.4%), and employment (54.3.%).
- Stigma also appeared to play an important role in social isolation.
- Most participants tried to conceal their condition (75%) and over half had not applied for jobs (54%) or higher education courses (50.3%) for fear of unjust treatment.
- Individuals with comorbidities reported significantly more stigmatisation than those without any co-occurring conditions.
- Experiences of stigma impacted their quality of life significantly and poorer quality of life was also significantly associated with anticipated discrimination. Finally, experienced and anticipated stigma were positively correlated.

Qualitative Findings

- humour that trivialises and reduces TS to simplistic notions mediates the construction and perpetuation of stigma; trivialisation in particular impedes the general public from understanding the complexity of TS;
- this leads to both subtle and overt discriminatory practice in micro-interactions and structural and institutional levels;
- people with TS attempt to manage their 'stigmatised identity' through concealment and self-stigma.

Conclusion

Stigma is an issue of substantial concern for people adults with TS. The experience of TS stigma dramatically impairs quality of life, manifests in different contexts and effects self-worth.

Recommendations

- There is a need for public initiatives that counteract stigma on different levels;
- Practitioners need to pay greater attention to how people with TS try to manage stigma;
- Future anti-stigma interventions need to consider incorporating humour as an educational strategy that will simultaneously entertain but also allow the audience to reflect on their prejudice and stigmatising behaviours;
- More studies that assess the effectiveness of TS anti-stigma interventions on specific community groups (i.e. healthcare professionals, secondary school children, college students, employers) are needed.

Society's collective response to TS need to change as barriers and restrictions still stem from prejudicial attitudes.

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